

Governor's Commission on Mental Retardation

**Strategies for Change:
Supporting Persons with
Mental Retardation Who Have
Health and Behavioral Challenges**

*A Report of the Commission's Public Hearing held on
October 25, 1994 at Holyoke Community College*

Strategies for Change:
Supporting Persons with Mental Retardation
Who Have Health and Behavioral Challenges

The Commonwealth of Massachusetts

GOVERNOR'S COMMISSION ON MENTAL RETARDATION

Commission Chair:
Marty Wyngaarden Krauss

Administrator:
Betsy Closs

Commission Members:
Members:

Charles Austin
Allen C. Crocker
Martha A. Field
Florence S. Finkel
William Gauthier
Mary McTernan
Robert W. Riedel
Richard E. Vincent

Staff

Pat Knipstein
Barbara Mazzella
Emily Micolonghi

Contributors:
Mary Ann Allard
Bridget Berry
Julie Flynn
Cindy Richards
Elise Sawyerr

The Governor's Commission on Mental Retardation
Saltonstall Building - Room 1103A
100 Cambridge Street
Boston, MA 02202
(617) 727-0517

Introduction

Over the past twenty years, the Commonwealth of Massachusetts has witnessed dramatic changes in the way services are provided to people with mental retardation. No change has had a greater impact than the downsizing of our state institutions. When the state schools began to reduce their census, persons with significant behavioral and medical needs remained, being deemed "too complicated" for the emerging community-based system. Today, the need for significant behavioral and medical supports continues to be the most common reason for institutionalization and re-admission to an institution. The development of a comprehensive, effective, community-based services system for persons with mental retardation and medical or behavioral needs remains a significant issue across the nation.

As created by Executive Order 356, the Governor's Commission on Mental Retardation is mandated to hold at least two public hearings annually. The purpose of these hearings is to focus on the quality of services for people with mental retardation including: "The quality of health, safety, and well-being of the Commonwealth's citizens with mental retardation; the quality of publicly-funded services available to these citizens; and the extent to which the private sector and the community at large provide opportunities for persons with mental retardation." Our second public hearing, held on Tuesday, October 25, 1994 at Holyoke Community College, was devoted to identifying innovative strategies and obstacles to supporting people with mental retardation and significant behavioral and medical needs. Both oral and written testimony was solicited from hundreds of individuals with mental retardation and other disabilities, family members, providers, advocates, clinicians, legislators and DMR representatives. A total of 41 individuals spoke at the hearing and another eight submitted written testimony. 115 people attended the hearing.

This report describes the complexities of the clinical services issue in four major sections:

- an overview of current practices;
- a review of the keynote testimony;
- a summary of the testimony from the public hearing; and
- concerns of the Commission.

Overview of Health Care and Behavioral Support Services for Persons with Mental Retardation

I. Health Care

Prevalence of Chronic Medical Conditions It is a widely held belief that people with mental retardation have many chronic complex and serious medical disorders which tax their health and require expensive, highly specialized medical treatment. Indeed, multiple studies confirm that people with mental retardation do have more on-going medical needs. For example, seizure disorders are found in more than 10% of people with mental retardation as compared with less than 1% of the total population. Nutritional failure, obesity, hypothyroidism, periodontal disease, chronic middle ear disease, arthritis, and mitral valve prolapse all occur with increased prevalence in persons with mental retardation and other developmental disabilities. Conditions such as gastroesophageal reflux, recurrent aspiration, and chronic pulmonary disease are found in significant numbers of people with profound developmental disabilities (Crocker, 1992). One study of 325 Massachusetts residents with mental retardation found that 62% had a chronic medical condition (Minihan & Dean, 1990).

Although it is understood that some people with mental retardation have a high number of chronic medical conditions, medical problems are usually modest in degree, and use of medical resources is often at or near use by the general public. Recent studies indicate that only about 15% of persons with mental retardation are considered to be within the "high consuming" group of people requiring ongoing monitoring and frequent access to specialized health care. In the Massachusetts study, 61% of those with chronic medical problems were rated as in stable health and required treatment by specialists less than once per year (Minihan & Dean, 1990).

Concerns about Those Who are Dependent on Medical Technology Due to dramatic advances in acute health care, more people now survive medical crises. One consequence of this increased survival rate is that greater numbers of people now rely on sophisticated medical technology including feeding tubes, respirators, oxygen, and intravenous lines. While such technology was once available only in hospitals, today most people can be supported in community settings. Although no figures for adults with mental retardation are available, it is estimated that 1 out of 1000 children in Massachusetts is dependent on medical technology; 50% of these children have cognitive challenges, 25% have severe cognitive challenges (Project School Care, 1994).

The state of Oregon has made a significant commitment to supporting people with chronic and severe medical needs in a community-based setting. As a result of a consent decree which transitioned children out of nursing homes, community homes were created for 35 adolescents who were dependent on tracheostomies, g-tubes, and ventilators. Twenty people were placed in provider-operated homes, and the 15 people most dependent on medical technology now live in three state-operated homes built across the street from a major hospital. The homes were designed to accommodate the special needs of those who lived there without compromising typical living space and include specialized kitchens and adequate areas for positioning mats and adapted wheelchairs.

Each house has five residents. One house is staffed 24 hours a day with nurses; the other two share 24-hour nursing. All allied health therapies are provided on site. Therapists are paid on a consultant basis rather than hired, and this has been a leading source of cost savings. Initially, 120 hours per month of physical therapy was required. As staff have been trained to follow the plans developed by professionals, physical therapy has been faded to 20 hours per month. Respiratory therapy continues at a rate of 90 hours per month of service. This ongoing high rate of utilization was not anticipated.

The Oregon program for young adults who are dependent on medical technology is funded through the Home/Community-Based Waiver. In 1994, to support one individual:

- ✓ Costs were \$182,500 in the institution.
- ✓ Costs were \$144,000 in the state-operated programs.
- ✓ Costs were \$ 96,000 in the provider-operated programs.

When the Belchertown State School in Massachusetts closed in 1992, people who were dependent on medical technology moved to "extensive support homes" which are located in close proximity to hospitals and provide 24-hour on-site nursing care. In these settings, nurses also assume the role of direct contact staff and assist with activities of daily living (ADLs), food preparation, and community activities.

In January 1996, members of the Governor's Commission on Mental Retardation visited two provider-operated homes for persons who had previously

lived on a "medical unit" at Hogan Regional Center. Both providers have nurses on staff who are available for team meetings, consultations with physicians, and for 24-hour emergency phone consultation. Physical, occupational and speech/language therapies are available on a consultant basis (via MassHealth-Medicaid). One provider has a "supplemental" contract with the local VNA to augment the Medicaid payment for therapy services. This contract pays for additional specialist hours which are used to complete assessments as well as for direct contact staff training. DMR pays between \$75,000 and \$80,000 annually for each resident in these homes.

While it is evident that highly specialized residential programs for people with mental retardation who are dependent on medical technology exist, most medically-involved people live at home and are cared for by family members sometimes with the assistance of home nursing care providers. While there are no figures for adults with mental retardation, estimates for children indicate that 70% of those who are technology-dependent live at home (Project School Care, 1994).

Health Care Financing and the Advent of Managed Care

Unlike other population groups, access to health insurance is not a barrier for people with mental retardation, since the overwhelming majority of adults with mental retardation are Medicaid eligible. In the Minihan & Dean study (1990), 84% of the sample relied on Medicaid and/or Medicare as the only sources of payment for health services. The reliance on this type of insurance poses challenges to people because it limits elements of the health care package which can be essential for people with mental retardation. Even in Massachusetts which provides generous benefits compared to other states, access to specialized mental health care, dental care, and allied health professionals especially physical, occupational, and speech therapists is limited. Failure to implement preventive programs and coordinate care yields a crisis-oriented system which includes a reliance on emergency rooms and expensive inpatient hospitalizations and treatments. Minihan & Dean found that out of the 267 Medicaid users, almost 25% experienced one or more instances when a health provider refused or was reluctant to treat them because the source of payment was Medicaid.

Prompted primarily by spiraling costs, the Division of Medical Assistance (Medicaid) initiated a mandatory managed care system in January 1993. Although managed care is commonly viewed as less than optimal for people with disabilities, elements of this system may prove beneficial to people with mental retardation.

Because of the emphasis on prevention, managed care organizations prioritize coordination of care. Because of capitation --whereby a medical group agrees to provide all the medical care for a pool of patients in return for a flat monthly payment-- patients cannot be refused treatment on the basis of their insurance coverage. These two factors --emphasis on prevention and capitation-- may reduce the instances of negative experiences documented in the Minihan & Dean study. In addition, the specialized health care needs of people with severe disabilities have been recognized by the Massachusetts Division of Medical Assistance (Medicaid). For example, Community Medical Alliance (CMA) is a Boston-based, managed care provider which specializes in treating severely disabled people. Led by Dr. Robert Master, who has dedicated his practice to treating people with severe chronic medical disorders, CMA is founded on the principle that intensive coordination and assessment by a person's primary care provider improves health and prevents costly "specialized" treatments. Each CMA patient is assigned to a nurse practitioner/physician team that provides total primary care and case management service in all settings including during inpatient hospitalizations. Patient satisfaction is remarkably high. A National Committee for Quality Assurance (NCQA) review of CMA notes: "Overall, the comprehensiveness of the benefits available under the CMA program, in conjunction with the significant efforts the provider makes to ensure the coordination of care across multiple settings makes this an exemplary program....Probably one of the most significant reflections of the effectiveness of this program was the glowing praise offered by its participants."

During the past year, Medicaid has contracted with CMA to provide health care coverage to persons with mental retardation. It was anticipated that significant numbers of persons with mental retardation would be enrolled in this service. Unfortunately, the Medicaid contract limits enrollment to persons who are only Medicaid eligible - not those who are both Medicaid and Medicare eligible. Since many persons with mental retardation are dually eligible, this limitation severely restricts access to the CMA service. One mother of an adult son who has mental retardation and significant behavioral challenges wrote about the prospect of losing the CMA coverage:

"When I first learned about Community Medical Alliance, I was very suspicious. It sounded too good to be true, not in line at all with the obstacles I had come to expect in seeking services for my son with his mix of disabilities. I just knew there must be some hitch. Either that or it wouldn't last. Since Michael enrolled in CMA in August 1995, his ongoing health assessment and treatment

has been excellent and reliable, timely and non-threatening for the first time in his adult life....I am certain it is more cost-effective than the alternative: fiscally for the Medicaid system, as well as physically and emotionally for my son."

While persons with mental retardation do have more chronic medical conditions than the population as a whole, it is important to remember these needs are generally stable and do not require intensive treatment by specialists. Among those who are dependent on medical technology, community-based models exist for high quality care. They are expensive and serve only a tiny portion of this group. Most people who are dependent on medical technology live at home with their families. Increased attention needs to be devoted to this group as well as to the impact of managed care on all people with mental retardation.

II. Behavioral Supports

A. Overview

"Challenging behavior" can be defined as any pattern of behavior which is an inappropriate, persistent response to internal or external stimuli; which is resistant to change; and which is detrimental to the individual or to his or her environment (Lowry & Sovner, 1991). Behavioral challenges are now viewed as having multiple causes-- they can be a direct result of a neurological or psychiatric disorder, they can be a result of environmental or relational distress or they can be a result of a combination of factors. The consequences of behavioral challenges are multiple and far-reaching. Behavioral challenges are often viewed as impediments to community placement, and they remain the primary cause of institutionalization or re-admission to an institution. Because of the intensity of staff support required to maintain the safety of the individual and the community, costs of placement for a person with a high rate of behavioral challenge can be double, or even quadruple, the average cost of placement. Behavioral challenges also interfere with the learning of new, adaptive skills and increase social isolation. In addition, the display of significant behavioral challenges impacts the community's attitude toward all persons with mental retardation, most of whom do not face such challenges. Literature on behavioral challenges is vast and encompasses multiple disciplines. The purpose of the following overview is to briefly summarize demographic information, history, and trends in the field.

Prevalence of Behavioral Challenges

In 1988, it was estimated that in the United States, 160,000 people with developmental disabilities exhibited serious behavioral challenges. The prevalence of significant aggression among persons with mental retardation is estimated at between 11% and 25%. Rates of self-injurious behavior range from 9% to 16%. The prevalence of both aggression and self injury are positively correlated with the severity of the disability, that is, the more cognitively challenged a person is the greater the likelihood that he or she will also have behavioral challenges (Lowry & Sovner, 1991). Some behavioral challenges are symptoms of mental illness. Studies of mental illness among persons with mental retardation suggest that between 10% and 60% of all persons with mental retardation also have a diagnosable mental illness. This compares to 18% of the general population (Stark & Menolascino, 1992).

The Rise of Behavioral Psychology

James Trent, author of a history of mental retardation services entitled

Inventing the Feeble Mind (1994), notes that while the earliest leaders in the field of mental retardation had been trained as physicians, they focused their efforts on education and training. By the 1870's, however, medicine and education had developed distinct roles in the treatment of persons with mental retardation. Physicians cared for persons who were multiply handicapped and those with severe and profound mental retardation, and educators trained those who were less challenged. Beginning in the 1930s, the relatively new profession-- the psychologist --brought to the field of mental retardation the tools of "intelligence" testing and behavior modification. By the 1960s, behavioral psychology dominated treatment. Because of its emphasis on the possibility of change, behavioral psychology brought a sense of optimism to the field. As Bradley & Knoll (1990) note, "...the implications of [behavioral psychology] radically transformed the lives of many people with severe disabilities because it provided human service practitioners with an alternative to mere custodial care. As experience was gained in using this approach clinicians realized that with the right intervention they were able to manage or control almost any behavior.... Usually, this attitude was guided by the best of human motivations: to improve the quality of life available to people by eliminating those actions that tended to alienate them from other people. Unfortunately, this technique was also used for the primary purpose of facilitating the management of groups of people in large facilities." While behavioral psychology was on the rise, the role of psychiatry diminished. After World War II, psychiatry in the United States relied increasingly on psycho-dynamic psychotherapy, extended "talk" therapy which focuses on early childhood development and its impact on adult life. This tool is of limited benefit to persons with cognitive challenges. Thus, the treatment of behavioral challenges among persons with mental retardation became narrowly focused on the manipulation of antecedents and reinforcers of behavior. Behavioral treatment was reduced to behavior management.

DMR and DMH Split

Recognizing the distinct needs of persons with mental retardation and mental illness, in 1987 the Massachusetts Department of Mental Health separated into the two distinct state agencies -- the Departments of Mental Health and Mental Retardation. At this juncture, nearly all persons with mental retardation who lived in mental health facilities were to be moved. DMR was charged with developing services to support the mental health needs of its clientele, including specialized residential programs, and regional clinical teams with both mental

health and behavioral expertise. The role of DMH was now limited to meeting the needs of persons who were in crisis through short-term hospitalizations. Over 160 persons with mental retardation left DMH facilities. Two-thirds entered the community system and nursing homes; one-third entered DMR institutional settings.

B. Trends

Increased Reliance on the Functional Assessment

Although the term "functional analysis" has been part of the behavioral psychologist's lexicon for over twenty years, the importance of the functional significance of behavior is only now being recognized. In this context, functional analysis means an assessment by which information is collected on the relationship between events which both precede and follow challenging behavior. This information leads to hypotheses regarding the function or purpose the behavior serves for the individual. Challenging behavior may, for example, produce desired objects (such as food), or events (such as attention), or changes in one's environment (such as a quieter setting). Challenging behavior may also function as a way to communicate the need for attention or assistance.

The Role of Person-Centered Planning

By focusing on the factors that maintain a challenging behavior, professionals increasingly recognize that the purpose of behavioral treatment may not be to help a person adapt to his or her current situation. Rather it is to support the person in leading a life in which the need for challenging behavior is moderated. Thus, ensuring high quality medical, neurological, psychiatric treatment *and* a high quality environment become the most critical elements of a service plan. One way to develop these plans is a process known as person-centered planning. While there are many different types of planning "technologies," all types of person-centered planning involve an intensive assessment by the people in the person's life including his or her support people, family members, and friends. The purpose of this process is to create a vision for what the person wants from life: where to live, how many people to live with, how much paid support is required, what role can unpaid supports play, and what the person wants to do with his or her day. The person-centered plan then becomes the foundation for enhancing fundamental change.

Meeting the Mental Health Care Needs of Persons with Mental Retardation

Through the pioneering efforts of persons such as the late Frank Menolascino, M.D., and current practitioners such as Steven Reis, Ph.D., Jeffrey Fahs, M.D. and Robert Sovner, M.D., it is evident that persons with mental retardation experience the same range of psychiatric disorders as the general population. It is also increasingly recognized that most psychiatrists can provide high quality care to persons with mental retardation if they are willing to view behavioral challenges as a symptom of a wide range of psychiatric disorders (including anxiety and depression), and to use behavioral tracking data to determine treatment efficacy. Perhaps most importantly, in order to effectively treat the person with mental retardation, the psychiatrist must be granted the time to develop collateral contacts with caregivers and family members.

Complex behavioral problems pose substantial challenges to persons with mental retardation. Meeting these challenges requires extraordinary efforts on the part of the person experiencing the challenge as well as from family members, direct service workers, and professionals who work with the individual. While there are no easy solutions or "quick fixes" on the horizon, through the focus on the multiple meanings of behavioral challenges and an increasing willingness to design treatment within the context of "quality of life," the optimism which had been the hallmark of behavioral psychology is once again renewed.

Review of Testimony by the Keynote Speakers

Testimony of Richard Lepore, private consultant,
formerly the Division Director for Community
Developmental Services of New Hampshire

"Florida has more certified behaviorists than any state in the country. And I was fond of saying that we were very happy to spend most of our resources on sending behaviorists into homes that nobody would want to live in and trying to change those people's behavior so that they could tolerate an intolerable living situation."

Citing his extensive experience with the service delivery systems of New Hampshire, Maine, California and Florida, Mr. Lepore focused his testimony on the needs of people with mental retardation who have behavioral challenges. He made the following recommendations:

Early Intervention A process of early identification and intervention should be developed. This process would begin with school and hospital social workers identifying children who may need intensive supports in the future. Following the assessment, the service system would provide adequate supports for families, so that institutional or other 24-hour placements are avoided. By doing so, Lepore asserted, *"you will reduce the need for complex interventions, and you will reduce the potential for your system to be dramatically stressed."*

System of Qualified Intervention Service systems need resource teams that can go to a family or group home and provide support and clinical expertise. In order to be effective, these team members must have professional training and adequate fiscal and staffing resources.

Role of Environment Noting that environment plays a significant role in behavioral difficulties, Mr. Lepore stated: *"we have to be responsive to the needs of individuals to have better quality environments and not spend our resources entirely on hiring qualified professionals to go in and change the behaviors of people to live in unsatisfactory environments."* He offered an example of how individualized supports could enhance the quality of a person's life and also reduce costs: There was a young woman who lived in Florida at a "behavioral residence"

costing \$60,000 per year. Her mother was very unhappy with the residence, especially the frequency with which her daughter was physically restrained. The mother wanted a different type of program, but no other model existed. A planning team was developed; the mother offered an apartment over her garage to provide housing; staff was provided at a 2:1 ratio. The young woman blossomed in this new setting, and behavioral outbursts declined. Staff was slowly reduced to a 1:1 ratio, and eventually, at the mother's request, staffing was further reduced on weekends. By fundamentally changing this young woman's environment, her quality of life improved dramatically, and the cost of her support was reduced to \$15,000 per year.

Quality Mental Health Care People with developmental disabilities need to have access to high quality mental health care. With 40% of people with developmental disabilities also having mental illness, mental retardation and mental health systems fail people who are dually diagnosed when they do not collaborate with one another. Mr. Lepore noted that mental retardation professionals are, at times, overly cautious in the area of psychiatric intervention. Experts in the mental health field are concerned that addressing the mental health needs of people with mental retardation will lead to additional long-term care placements within the mental health system. Mr. Lepore added that people who are dually diagnosed need access to high quality, short-term, in-patient hospital placements.

Role of Specialized Residential Services Mr. Lepore rejects the behaviorally-based home or institutional unit. This model was originally designed to promote stabilization and skill development which would facilitate re-entry into the community. However, the result of these behavioral units is long-term institutional placement. For example, the Pineland Center in Maine was originally designed for 20 people and grew to a census of 80, because so few people admitted were able to return to the community.

Mr Lepore concluded his testimony by urging that the focus be on environmental quality. *"[We need]...an ongoing commitment to change our current environments to develop and maintain healthy environments which will reinforce parts of our ongoing community system for people who struggle with developmental disabilities and behavioral issues."*

Testimony of Beth McArthur, Director of Planning and
Development for
the Department of Mental Retardation in Connecticut

"We have moved from an era when people mostly thought about trying to discipline or control people, to fix people with challenging behaviors, or to suppress the behaviors rather than looking at what kind of support does this person need. What is the person trying to tell us? And what is it that we ought to be teaching the person to do as an alternative to this?"

Ms. McArthur presented a framework entitled "Changing the Outcomes" which outlines the type of strategies Connecticut's Department of Mental Retardation employs to increase the opportunities for persons with mental retardation. During her testimony, she reviewed the key aspects of this framework.

Lifestyle Change Ms. McArthur identified a major paradigm shift which renews the focus on the choices, relationships, and control people with mental retardation have in their lives. The goal for Connecticut's DMR is to develop an in-depth understanding of what the identified person needs and wants, and then to plan for the opportunities needed for a positive lifestyle change.

Support Readiness versus Person Readiness This refers to a change in the way supports are provided. Enhancing an individual's participation in "real" life is emphasized over training in artificial situations designed to "prepare for life."

Functional Analysis Functional Analysis assumes that most behavior is meaningful, and each assessment begins by asking the question: what is the purpose of this behavior? The behavior is then labelled in four ways: seeking attention, seeking sensory stimulation, avoiding task or situation, and communication.

Ecological Analysis and Setting Events This is also a form of behavioral assessment whereby the environment is carefully examined with the idea that it is often much easier and more productive to change the physical environment or the antecedents (the events that lead up to a behavioral episode), rather than try to fix the person or get them to adapt to the environment.

Learning Problems This is a form of treatment planning with a focus on what can be taught to replace a negative behavior.

Communication Ms. McArthur noted that often an individual will communicate that something is wrong by exhibiting challenging behaviors.

Support with Humility Ms. McArthur emphasized that we must acknowledge the difficulty of the behavioral challenges in each person's life, *"we sometimes come in with a sweeping, powerful attitude that we can control and manage these behaviors in other people when we know that for ourselves it is often not an easy thing to do."*

Case Example Ms. McArthur reviewed the use of this framework by relating the story of a young man who had a significant history of aggression. He lived in a six person group home and would tear apart the walls and furniture; he would hurt himself and others. Both his housemates and his staff were afraid of him. Through functional analysis, his team found that this man needed more time outdoors. They also realized he needed some way to escape noisy activities in the kitchen. He needed to have people pay attention to him when he was whining, rather than ignore him which was the advice of his psychologist. Whining, for him, was a form of communication that something was not right. *"And miraculously when people started listening to him, the behaviors began to decrease."* The staff made changes in both the kitchen and backyard to make the environment better suit his needs. Now this man can go out into the community with ease, he works as a delivery person when he used to be afraid of new places, his sign language abilities have also increased significantly so he can more directly communicate his needs.

Ms. McArthur concluded her testimony by reminding the audience of the on-going nature of this process. *"I don't want to cast this like we had a grand scheme when we started off...that we know exactly where we're going, and we know all the pieces we need to put in place. Because there are people who still baffle us....You do have to keep working at it. You never quite get it solved."*

A Summary of the Testimony

I. Major Themes

The speakers who testified included parents, people with developmental disabilities, advocates, and professionals. They spoke out of a concern for people with distinct needs, yet woven throughout their testimony was a universal premise: *the key to successful intervention is a focus on the individual*. The stories of their lives, their hopes for the future, and their recommendations to the Commission reflect three common themes.

- Avoid labels.
- Begin with a profound understanding of the person you are trying to assist.
- Collaboration between all parties, especially the person who is being supported and his or her family, is essential.

Labels as Obstacles Denise Fielding, who spoke movingly of the changes in her son's life, expressed her disdain for labels such as "mental retardation." She asserted that *"one of the biggest things that needs to happen...is that the labels that have come to be associated with people with disabilities need to be eliminated. It sabotages their growth; it sabotages the way in which they're able to live their lives."* Ruth Ann Lee, a self-advocate and former resident of Belchertown State School concurred. Ms. Lee recommended that the word "retarded" be avoided. She spoke of an experience in which she was called "retarded" connoting for her that *"I should be watched 24 hours a day and locked up."*

Begin with a Profound Understanding of the Individual:
Listening and Planning Beverly Stevens, the Regional Director of Mentor Clinical Care, summarized the core theme of the hearing: *"The bottom line...is that it all starts with the individual."* David Chevalier, a DMR service coordinator in Western Massachusetts suggested that the process of beginning with the individual is not a *"quick fix,"* but a long-term commitment to *"establishing what is meaningful, and what's real to this person and giving them a sense of choice and some sense of control..."* During the hearing, Mr. Chevalier recounted the story of a woman who lived at Monson Developmental Center. She had multiple medical needs and a *"lot of pain, chronic pain."* The woman had

lived in an institution for forty years, and she wanted to move. She first lived in a group home setting and then was able to get her own apartment with a combination of DMR and Personal Care Assistant (PCA) support. Since she has lived on her own, she has begun working part-time and has become active in various committees, but most significantly, her pain management needs have decreased.

Jeanette Gilmartin, a parent and advocate, recounted the story of a 72-year-old woman who, after living in an institution for 50 years and then a group home for 15 years, ended up moving to her own home. This came about *"only after I began to listen to her. I began to listen to what she wanted and instead of looking at all the whys it couldn't happen, I went back to the KISS theory--Keep It Simple, Stupid--and we were able to make things happen for her."*

Denise Fielding described the planning process for her son who had spent most of his life in institutional settings. Although Ms. Fielding had always wanted a non-institutional placement for her son, no model was available which met his needs. When her son approached age 22, she applied to participate in a joint pilot project between DMR and the Department of Education. The goal of this project is to use an intensive planning tool called Individual Service Design to find ways to support those who are not currently served in the community. First, Ms. Fielding visited other living arrangements both in Western Massachusetts and in New Hampshire. Then all the people in her son's life gathered at her home and, with the help of a facilitator, answered three questions: Who is this young man? What are his needs? How can we achieve them? The benefits for her son are obvious: he now lives in his own house with two other roommates. He interviews and hires the people who support him, and his mother says *"he's doing things that he never would have ever been able to do."*

The results of intensive listening and individualized planning are often unexpected. John Reis, the program director at Westport Associates described a man he calls "Bob." Bob had a significant history of behavioral problems. In his last community placement he was restrained daily by staff. *"There are a lot of things that we did to try to improve Bob's life, one of which was listen to him. What I wasn't prepared for was when Bob came to me one day and told me he wanted to get married...."* Bob's team met and drew up a plan that said Bob would be ready to get married in about seven years! When this plan was reviewed with Bob, *"he took a pen and paper, and he wrote on it: No more group home. Closed. Marry Norma."* It turned out that marrying Norma really was possible; his future mother-in-law supported the marriage, and the couple moved into an apartment adjacent to Bob's in-laws' house.

The Testimony of Mark Nasjleti

"As a person who owns his own home, my name is Mark Nasjleti, and I own a wonderful condo in Chicopee near Westover Air Force Base. All my life, I wanted a safe community to live in, not just for myself but for others who live there too.

I always wanted to live in a place where things are happening. A place with stores, restaurants, a gym and a place to work. I wanted to be able to walk around, meet people my own age and have things to do. I wanted to make friends. I wanted to go places in my own neighborhood when people would know my name and act glad that I dropped in.

I first heard about Ridge Village from my case coordinator at DMR. Right away, I wanted to see the condos. I met Kevin Leahy and Gina at FOR Community Services, and Gina made me feel excited about the possibilities. I went to lots of meetings at the bank. I began to shop for my own furniture and kitchen stuff. It was a little work and lots of fun. My dad painted the dining room table, and my roommate put together the bookcases. I'm moved in and enjoying it. Thank you."

Mark's father, David Nasjleti, added: "Mark arrived at this point at age 25 itching to play an adult role.... Many were helping Mark develop a broad range of self-help skills. However, as long as he continued to live in a protected, parent-dominated environment, it was impossible for him to develop further, to be the person he wanted to be, to develop his own style. Unlike a group home from which people can be moved willing or not, and unlike an apartment where neighbors come and go, home ownership means getting to know the people who live or work in your neighborhood.... This stimulating life, full of diversity, replete with choices and rich with possibilities has been achieved through a partnership among government funded and privately supported agencies and programs.... A partnership that includes us, his very active parents."

Intensive Collaboration Robert Yorke, a clinician from Wrentham Developmental Center, spoke about his interdisciplinary clinical team. Comprised of representatives from a variety of clinical professions, the goal of this team is true collaboration which produces effective treatment plans grounded in a multi-dimensional understanding of the problem behavior. Several other speakers expounded on the need for intensive collaboration, not simply among professionals but also with the individual and his or her family. Stephanie Porter, the Director of Project School Care, stated: *"We have also learned that families know their child and young adult best. The child and the family are an integral part of the education and health team."* Parents including Denise Fielding, Carol Gerety, David Nasjleti, Joanne Murphy, and Jeanette Gilmartin all emphasized the importance of partnerships between providers, families and DMR:

"The resources of a family are always limited. When a family embraces the challenge of supporting the full life of a person like Mark, those resources are limited not just by money but by human energy and time. This partnership is the only way to go." --David Nasjleti

"I just want to say that I am so happy that we are now in an environment where the DMR and agencies and people are willing to listen to families and help us to listen to our children and respect them and understand what they want and to work together for them." --Jeannette Gilmartin

Leslie Kinney from the Franklin County Arc suggested that it is essential for people with disabilities to have support through natural networks as well as through purchased services. Noting that these so-called "natural supports" do not obviate the need for paid services, *"freely given relationships are enduring, they are strength focused rather than deficit focused. They hold the service system accountable and are responsive to the individual and protect the individual."*

The Testimony of Four Self-Advocates

John Patrick: *"I lived at Belchertown State School for 17 years. I know a lot of people that used to live there. People would say to them that they will not make it out in the community at all. And here they are today living out in the community. Some of them are living on their own....I think that people that have a hard time seeing or that cannot walk or that cannot hear well at all should have a chance to live in the community as well as everyone else, even if they are having a behavioral problem. If anyone asks me should even people with behavioral problems live in the community I say yes. I think so. I think they should have a chance because they are not different than we are."*
[Mr. Patrick passed away at the end of 1995 following a lengthy illness.]

Doreen Stoney: *"I like it at Monson Developmental Center. There's a lot of good things I do there. We go--we work every day and we go downtown on Saturdays. And I have a lot of friends....And I used to live in a group home years ago but I'm not in one now. I'm staying right where I am at Monson. I like it there better. And I am healthy. I used to be real sick years ago, but I'm getting better now."*

Annette Bosquet: *"I'm Annette Bosquet. And I know quite a lot of people over here. I would like-- I'm 68 years old and I would like to know if you would put me in a home in Greenfield before long--would you help me please?"*

Ruth Ann Lee: *"I was in an institution for a long time. I like being out in the community. But there is one thing that I'd like to say that I'd like to have the word 'retarded' changed completely....I was in a restaurant one day, and this woman called me retarded, and I should be watched 24 hours and locked up, right in front of everybody in the restaurant. And I didn't get upset. I just walked out. And I wrote a letter to the newspaper, and I told them that I was called retarded in a restaurant. And I got about seven or eight letters back from everybody out in the community that [because] I really spoke up...it meant I wasn't retarded....I'm showing the people that I should not be locked up. I should be up living like normal people."*

II. Recommendations for People with Particular Challenges

A. Supporting People with Medical Challenges

Community-Based Residential Services

Sheila Ste. Auben, the Executive Director of Westport Associates, a community-based provider, described her agency's approach to providing support to people with medical needs: *"The way we deal with medical needs is the way we would deal with my own medical needs. We get people the best medical assistance that we can find. Sometimes that's very local; sometimes it means going to Boston. Sometimes it means a specialist; sometimes it means when people go to the hospital we stay with them."* Ms. Ste. Auben told the story of a man for whom community placement was actively discouraged. She described someone who is quite physically challenged: *"He is completely contracted. He is a quadriplegic. It takes 45 minutes to feed him breakfast. He cannot speak. He has no voluntary movement."* The provider was told that he had pneumonia, skin breakdowns, and impactions constantly. In the past 14 years that Westport has supported him, none of these conditions has recurred. *"He is a very successful member of his community. He uses a communication computer now-- a voice activated communicator. He is on several committees in his community. He has been to New Hampshire, to Atlantic City, down on the Cape, camping in Vermont, and Western Massachusetts. He lives a completely full life in the community."* Ms. Ste. Auben noted that *"This is not magic. This is simple. It's not innovative. It's basic human values. We stand by people. We get to know each person as best we can and really try to understand what they're telling us and what they need, and what they want and never give up."*

Paul Hudson, President of the Kennedy-Donovan Center, raised a number of issues that his agency is encountering:

- **Changing Needs of Residents** Residents who have lived within a community-based program for years are now aging and have increased medical needs. To provide for these needs and to increase the support requires additional money, and often this is not available. He also noted that when one group home resident becomes dependent on medical technology, it impacts the entire house, *"...we try to make a home situation and at the same time, to provide medical intervention."*

- **Salary and Training of Direct Contact Staff** Mr. Hudson stated that the person we considered "challenging" to the community system 15 years ago is now considered "typical," yet with these increasing challenges and enormous responsibility, the training and salary for direct contact staff have changed little.
- **Use of Nursing Homes and Hospitals** The Kennedy-Donovan Center has supported individuals whose medical needs have dramatically increased. Sometimes the family members request nursing home placement, but DMR has been committed to keeping people out of nursing homes. Mr. Hudson suggested that many families opt for nursing home care for loved ones, and he "*would not rule that out as a legitimate resource.*" Mr. Hudson also noted that hospitals often refuse to take a person with a cognitive disability unless staff can be provided to stay with that person. This situation is challenging for providers who generally have limited personnel resources.
- **Enhance Training to Medical Community** Mr. Hudson recommended that programs be developed that will inform and encourage medical personnel to treat people with cognitive disabilities effectively.

The Use and Availability of Professional Therapists

Two speakers voiced concerns about access to occupational, physical, respiratory, and speech therapies for people with mental retardation. Both speakers are professionals in the field and worked previously at Belchertown State School. Linda Tsumous is a physical therapist, currently the Chairman of the Physical Therapy Department of Springfield College. She is also the guardian for a person who lives in a community residence as well as a member of a human rights committee. Ms. Tsumous asserted that there is a "*serious erosion*" of clinical services available from Commonwealth employees for individuals with developmental disabilities. In addition, many community-based therapists often have little experience working with those who are multiply disabled. She noted that we should not return to an institutional model, but advocates for a "*medium ground which allows for potentially the creation of regional systems that have teams of providers who consult, design, and develop and potentially provide direct services for the individuals with developmental disabilities.*"

Jean Rosenberg-Ashlaw is an occupational therapist who worked at the Belchertown State School. She is guardian for a man with multiple needs who lives in a staffed apartment with 24-hour nursing care. Her testimony described a significant reduction in both the quality and quantity of her ward's therapy services which has led to skill deterioration. Echoing Ms. Tsumous, she noted that there are simply too few licensed professionals in the state system to effectively treat these severely challenged clients.

Children Who are Dependent on Medical Technology

Stephanie Porter, Director of Project School Care at Children's Hospital, spoke at the hearing. She summarized the findings of her work:

- Families know their child and young adult best. The child and the family are integral parts of the education and health team.
- When health, education, and community systems collaborate, more comprehensive planning occurs.
- Discussions on financing and reimbursement issues that support children with special health needs and disabilities must continue.
- In order to care for children in schools, educators and school nurses need support and training.
- To enhance community partnerships, state agencies, tertiary centers and community agencies need to work together to adopt innovative models of caring for children.

Focus on: Project School Care

Project School Care (PSC) was established to foster educational opportunities for children who use medical support technology. The project is based out of Children's Hospital in Boston and is funded by federal monies, the Robert Wood Johnson Foundation, and the Dyson Foundation of New York.

Medically challenged children, who the project estimates to be 1 out of 1000 children, are now living longer due to advances in medical science and technology. Some of this technology--feeding tubes, respirators, oxygen, intravenous lines--which had previously been seen only in hospitals are now in community schools. Half of these children have some type of cognitive impairment; 25% are severely cognitively disabled; 77% of these children live at home.

It is often a complicated process for these children who need frequent medical attention and assistance to attend school. Project School Care provides consultation to the school staff who are facing such a challenge. A PSC nurse goes with the school nurse to do a home visit and assessment. A health care and emergency plan is then devised, and training is provided for all who are involved in the child's care including those who do the transportation.

Carol Gerety, a parent of a 26-year-old woman with cognitive and physical challenges, described the hard work of true community inclusion. Her daughter was the first person in her school system to be fully mainstreamed. She participated in a wide range of school activities including managing several sports teams and singing in the choir. She then went to Massachusetts Hospital School in Canton to develop her independent living skills and is now living independently with assistance from Personal Care Assistants.

Renee Walbert of Franklin, Massachusetts was not present at the public hearing but submitted written testimony. She is a parent of three children, two of whom have developmental disabilities and significant medical needs. Her son has cerebral palsy and lung impairments; her daughter has a rare blood clotting disorder, fetal alcohol syndrome, is legally blind and has no stomach and short intestines. Both children are tube fed at night. She wrote: *"I am not a nurse, but I know more about their needs and can do all of their cares better than any individual professional who may know only part of their needs. I have used PCA services for my son, and this is the model we ought to go with. It gives family control, individual dignity, and is more cost effective than other models."* Ms. Walbert suggested a change in the way PCA services are paid for. Noting that currently PCA funds are channeled through a proprietary agency such as an independent living center, she suggested that the monies be paid directly to family

members or at least pay the PCAs directly from the state. She feels this would reduce administrative costs and reduce the time a PCA waits to be paid.

B. Supporting People Who Have Behavioral Challenges

"Essentially, people with challenging behavior are critics of our service system and instead of blaming them, we might use them as an opportunity to review what we are doing and for whom we are doing it." -- Herb Lovett

The importance of intensive listening and allowing a significant measure of individual control was repeated throughout the hearing. In his written testimony, Herb Lovett wrote: *"Time after time, I have found when people are taken seriously, when they are respected, when their behavior is interpreted, understood, and responded to accurately, when they are engaged in a mutual dialogue rather than subject to unilateral schemes of 'behavior management' somehow, as if miraculously, they become more ordinary. I know any number of people who have had 'severe reputations' who have shed them when those supporting them listened more carefully."*

Choice and Group Living Situations

Joan Beasley from START Clinical Services suggested that individualized support usually means alternatives to group homes. Beasley stated: *"It seems to me that people with developmental disabilities and mental health or behavioral issues don't do very well being paired off with people who have similar symptoms as themselves....I think, just like all of us, we like to live with people who match our strengths, not our weaknesses. Where what we like to do is not based on what's wrong with us or what we see is lacking in us....For some reason in our wisdom we paired people up based on their needs instead of their wants, and that was a big mistake. So I don't believe in group homes at all. I think people should live in groups whatever size they want at their own choice, but not based on our own convenience as providers or as the Department."*

Focus On: START Clinical Services

START is an acronym for Systematic Therapeutic Assessment Respite and Treatment. Its primary funding source is the Department of Mental Retardation, and it is operated by Greater Lynn Mental Health and Retardation Association, Inc. The area that START covers is DMR's northeast region. It serves children and adults who have developmental disabilities and either mental illness and/or severe behavioral difficulties in this 750 square mile range. START provides a wide range of services including:

Clinical

clinical consultation

crisis prevention planning

outpatient mental health services

psychiatric assessment

Crisis

emergency evaluation

crisis intervention

psychiatric hospitalization

Respite

short-term

planned & emergency

in-home

foster family

START's philosophy involves a systematic approach including the belief that the entire network involved in the individual's life needs to work on the solution to difficulties. The most effective collaboration occurs when the system works together toward change. Quality diagnostic work coupled with solid crisis prevention, specific to both environmental and psychiatric aspects of the individual, can *prevent* crises from occurring while improving the quality of the individual's life. Furthermore, START's treatment philosophy is based upon sensibly meeting the expressed needs of individual consumers. The staff at START operate from a belief system in which behavior can be a result of a multiplicity of problems, and that there is no specific diagnosis or treatment modality that works with all consumers.

START's crisis prevention planning credo is that all consumers should have crisis prevention plans. The crisis prevention plan is a tool by which crises can be averted through proactive intervention as well as a working agreement among providers that clearly delineates roles and responsibilities.

Sheltered Day Placements

Herb Lovett noted that sheltered placements are often the only option available for people who have challenging needs, yet this type of placement increases behavioral incidents. *"Incredibly, not everyone with a disability wants to 'work' sitting at tables doing assembly from 9 am to 3 pm and for almost no money or no money. We also need to stop funding 'day wasting' centers and get people either real work or access to activity that has meaning for them. When we stop putting people into programs of endless training which rarely leads to real work, we will have fewer behavior problems."*

Functional Analysis

Many speakers including both keynote testifiers emphasized the importance of functional analysis as a tool to treat challenging behavior. Jeff Robinson, an Assistant Vice President at Vinfen Corporation, presented a case example which demonstrates the efficacy of this assessment tool. Mr. Robinson reviewed the life of a man he called "Jim." Jim had a long history of institutional placement, and psychological testing revealed an IQ of less than 30, the functional equivalency of two years of age, diagnosis of autism, and profound mental retardation. Jim acquired numerous labels including: non-communicative and tensely aggressive, stubborn, angry, easily frustrated, non-compliant and dangerous. Even when heavily medicated, he engaged in intense and frequent dangerous and destructive behavior.

When Jim transitioned from the institution, Vinfen's treatment team provided behavioral shaping and replacement skills. Through intensive positive programming, Jim's maladaptive behaviors decreased in both intensity and frequency, but they still substantially restricted his ability to really participate in community life. Mr. Robinson noted that through the advent of functional analysis and functional communication training, Jim was able to make enormous progress. The functional analysis of Jim's behavior suggested that it was motivated by the desire to escape. So the team taught Jim the sign of "break." Thereafter, whenever Jim signed "break," he could leave the work area. One day, Jim taught the team an important lesson: *"He was working at the table one day and rather than signing 'break', he signed 'food'. I remember that moment vividly, because we all looked around at each other not sure what to do. And someone had the bright idea of handing him some food -- a tray with different items on it-- and he did exactly what you might think. He ate. And then he signed a few more times and continued eating. All the while, though, he was working. He had taught us that behavior can be multi-functional: that he didn't want a break*

from work, he was merely hungry."

Since this time, Jim has continued to make tremendous progress. He now lives in Brookline with three housemates. He is medication free. Both the intensity and frequency of his behavior are such that he can go out into the community frequently; he loves to go to Dunkin' Donuts, stores, restaurants; at home he likes to listen to music and play with his dog.

C. Supporting People who have Mental Illness as well as Mental Retardation

"...the time when you can split behavioral from mental health services is long gone. For someone to call themselves a mental health specialist and not understand functional analysis doesn't make sense. Nor does someone that considers themselves a behavioral specialist who does not know how to diagnose psychiatric disorder." -- Robert Sovner, M.D.

It is clear from the literature and testimony at the hearing that mental illness accompanying mental retardation is not unusual. Dick Lepore noted that in one region of New Hampshire, 40% of people with mental retardation also had mental illness. START Clinical Services found that 56% of people who received services in Region 3 had psychiatric disorders. Robert Sovner, M.D. estimates that in the United States between 20% and 40% of people with mental retardation also have a diagnosable mental illness.

Collaboration Between the MR and MH Systems

Joan Beasley of START Clinical Services remarked that cooperation between the DMR and DMH systems is crucial for the successful support of people with both disabilities. Many speakers suggested that the tension between behaviorally trained clinicians and traditional mental health clinicians needs to be channelled into a model of collaboration.

When DMR and DMH separated in 1987, an inter-agency agreement was designed to promote high quality services for persons with both mental retardation and mental illness. Bernard Graney, formerly the Executive Director of Pioneer Developmental Services and now on the faculty at Springfield College, suggests that this agreement be re-examined.

"Massachusetts would do well to attend to its unfunded mandates that already exist including the DMR/DMH inter-agency agreement concerning persons

with dual diagnosis and challenging behaviors. [It] needs implementative commitment, resources and planning."

Increase Resources

Several speakers advocated for an expansion of community-based services including:

- Outpatient diagnostic and treatment services with both behavior and mental health interventions available concurrently.
- Home-based crisis intervention.
- Acute psychiatric inpatient services that promote stabilization and successful reentry into the community.
- Adequate respite for families and care providers to prevent hospitalizations.
- Residential programs with psychiatric input where people who may be aggressive or have the potential to harm themselves can be contained.

Focus On: The Neuro-Behavioral Unit at Boston Specialty Hospital

Dr. Claire Levesque, Director, testified at the public hearing. The Neuro-Behavioral Unit is an inpatient service designed to meet the needs of persons with cognitive impairments, including adults with mental retardation and dementia. The multicultural interdisciplinary team includes a neurologist, a psychiatrist, internists, behaviorists and a neuropsychologist, specially trained nurses, social workers, and a full rehabilitation team.

The unit is designed to diagnose and treat patients with cognitive disabilities who also have medical problems, functional deteriorations and behavior problems including aggressiveness, self injurious behavior, wandering, and sleep disturbances.

Its goals are to treat the medical and psychiatric conditions of the cognitively impaired and return them to the least restrictive community living arrangements. The team encourages participation of providers in all aspects of treatment planning and also provides outpatient behavioral planning.

Concerns

Complex chronic medical conditions and serious behavioral problems challenge persons with mental retardation, their families, and their support providers. There are no "quick fixes"; these conditions are typically lifelong, and require sustained, consistent support by caregivers who are both knowledgeable and compassionate. The testimony at the hearing revealed that high-quality lives for people with complex challenges are indeed possible. The public hearing, site visits, and interviews reveal that pockets of excellent service provision are to be found throughout the Commonwealth. Clearly the current system has the capability to provide services of unprecedented quality.

Persistent concerns have also emerged, and we call attention to four specific areas:

- the on-going need for individualized planning, especially for persons with significant behavior challenges. The Commission supports the efforts of the Department of Mental Retardation to implement a program which will train many service coordinators in Person-Centered Planning. Now in its second year, this training will enable the Department to provide the services of a professional in person-centered planning to any individual or family that wants such a plan.
- the lack of data and information on costs for these sub-populations. Currently, the Department of Mental Retardation, through its Consumer Registry System (CRS), documents physical challenges, and hearing or vision impairment, but does not include information on mental illness, behavioral challenge, seizure disorder, or dependence on medical technology. Refining the data collection tool would enable the gathering of more detailed information which would in turn make possible a comprehensive analysis of support options--including a comparison of costs and quality outcomes.
- the quality of psychiatric services for persons with mental illness and mental retardation. During the hearing and interviews, people voiced concerns about the consistency and quality of psychiatric care for persons with mental illness and mental retardation. By all accounts, the successful treatment of mental illness among persons with mental retardation requires detailed, multi-disciplinary assessments and adequate time to make

collateral contacts with family and service providers. The Commission is concerned that the needs of citizens who have mental retardation are not being met because current reimbursement rates are not flexible enough to permit adequate time for on-going assessment.

- access to occupational, physical, and speech-language therapy services. Several testifiers expressed concern about difficulties in accessing therapy services for their loved ones who lived in DMR-funded residences. Clinical professionals in Western and Eastern Massachusetts interviewed by the Governor's Commission staff agree that access to therapists who are available and trained to work with this population is a problem. Training of para-professionals, such as certified occupational therapy assistants (COTAs) and physical therapy assistants (PTAs) is a promising solution. In addition, the use of a small supplemental contracts, funded by DMR, which pay for additional therapy hours for staff training and assessment appears to be a successful way to ensure high quality services at a reasonable cost.

References

- Bradley, V. & Knoll, J. (1990). Shifting paradigms in services to people with developmental disabilities. Unpublished manuscript, Administration on Developmental Disabilities, United States Department of Health and Human Services, Washington, DC.
- Crocker, A.C. (1992). Expansion of the health-care delivery system. In L. Rowitz (Ed.), Mental Retardation in the Year 2000. New York: Springer-Verlag.
- Lowry, M. & Sovner, R. (1991) The Functional Significance of Problem Behavior. The Habilitative Mental Healthcare Newsletter 10(10), 59-65.
- Minihan, P.A. & Dean D. (1990). Meeting the Needs for Health Services of Persons with Mental Retardation Living in the Community. American Journal of Public Health 80(9), 1043-1048.
- Stark, J.A., & Menolascino, F.J. (1992). Mental retardation and mental illness in the Year 2000: Issues and trends. In L. Rowitz (Ed.), Mental Retardation in the Year 2000. New York: Springer-Verlag.
- Trent, J. (1994). Inventing the Feeble Mind. Berkeley and Los Angeles: University of California Press, Ltd.

